DATE:FEBRUARY 26,2007

1. LOCATION:CT STATE LEGISLATIVE OFFICE BUILDING

CAPITOL AVE

HARTFORD,CT

SUBJECT: PUBLIC HEALTH HEARING ON:

PROPOSED BILL #5747-REINSTATEMENT OF MANDATORY REPORTING OF POSITIVE LYME DISEASE CASES BASED ON CDC CRITERIA

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PROPOSED BILL #6701- ESTABLISHMENT OF CT LYME DISEASE TASK FORCE TO STUDY & RECOMMEND A STATE-WIDE PLAN FOR CONTROLLING LYME DISEASE

WRITTEN TESTIMONY OF ELIZABETH A. WHITE, RN, APRN

LYME DISEASE is & has been a major public health issue in our state. It is difficult to believe that we have not continued to mandate the laboratory reporting of positive test results. We can never know the incidence -that is the # of new cases at any period of time - week,month,quarter,year. Niether can we know the prevalence -eg the total# of cases at any period of time-week,month;quarter,year. Equally important ,we are not able to identify those areas of greatest risk-cities/towns, districts & counties. Since we lack mandatory reporting of +test results the # number of new cases is FALSE & can only be considered as grossly under reported. Reinstatement of laboratory reporting of +test results provides us with best possibility of the accurate rate of incidence. Also, it can/should provide necessary data identifying the areas in the state with the highest rates of infection. Therefore the areas with the highest rates of what I call TOXIC TICKS/ infected ticks. Without this data, we are greatly hampered in knowing the degree to which this is endemic in specific locations & therefore the degree of risk of infection that anyone is confronted within these locations.

WITHOUT PUBLIC REPORTING OF THIS DATA CITIZENS CONCERN FOR CONTRACTING THIS INFECTION CAN EASILY RECEDE FROM CONSCIOUSNESS RESULTING IN FORGETTING THE NEED FOR SELF PROTECTION, IDENTIFYING EARLY S&S & THE IMPORTANCE OF SEEKING AS EARLY AS POSSIBLE MEDICAL CARE. THESE ARE CRITICAL ACTIONS CAN PREVENT DELETERIOUS & LONG LASTING SYMPTOMS OF THE HEART OR JOINTS OR THE BRAIN.

This would provide the necessary focus for Intensive/High Visibility Public Health Education Programs on:

- -Self protective actions necessary to reduce the risk of exposure
- Identification of early s&s of possible Lyme Infections
- -Importance of seeking early medical evaluation/treatment

Cost effective considerations for medical evaluation/treatment follow up

Recommendations on the need for medical follow up treatment can be given at the time of the initial medical evaluation. Follow up is the responsibility of the patient /guardian-limiting the needless cost for follow up by medical personnel. This procedure could provide a cost effective approach for both accurate reporting & follow up medical treatment. Cost effective systems can be set up for reporting of sensitive infections. In one such model - patients are assigned case numbers & given a callback telephone # for test results. A similar system currently exists one highly sensitive communicable infection. Although, Lyme is not a person to person communicable infection, patients should be informed that other family members/friends may have been exposed to contaminated ticks carried on patient or household pets especially outdoor cats. If they develop symptoms consistent with Lyme disease they too should be tested. Ticks should be submitted to local health departments for testing of infection(ixodes scapularis).

The effectiveness of education can be evaluated on basis of data provided by mandatory reporting of + laboratory tests results.

In this age of technological sophistication it is possible for data collection

& analysis to be done & communicated accurately & speedily. We hear & watch ticker tape on our TVs reporting #s of cases in salmonella outbreak in a number of states & related to identified food as well as data on rates of infectious diseases(SARS/Bird Flu) across the world. I certainly hope that we can begin to resume the most basic reporting of this infectious disease that is endemic in our own state. There is no need to identify individuals with + tests results , since Lyme disease is not a communicable infection. The anonymity of test results can decrease possible concern of some citizens re:insurance, educational, employment matters.

We continue to witness a rampant spread of LYME throughout CT.As well, there are increasing numbers of us who have tested + for babesiosis &/or bartonella.Two other tick borne diseases that require treatment & further complicate the response to treatment of Lyme. Those of us in the LYME community have been & continue to be very concerned about the under reporting in CT.Lyme disease is the fastest growing bacterial infection in the USA. Even with the current reporting system, CT. ranks in the top three in the nation. A gold standard for diagnosis & treatment of LYME DISEASE has yet to be established. The jury is still out. Hopefully in the future a definitive treatment will be determined. In the meantime, let the hippocratic oath(first do no harm) be the guide.Mandatory surveilence is the first step addressing Lyme disease as a serious threat to the health of the citizens of CT.

A delay in &/or insufficient treatment has caused this complicated bacterial infection to take hold & cause bodily harm. In the case of children, the consequences for them & their families can be devastating, dimming bright hopes for their future. For adults the results are also devastating as they struggle with necessary adaptations in major aspects of their lives.

Disabling symptoms, left untreated, cause a disruption in most aspects of Lyme patient's lives & have a deleterious effect on their previous level of participation in the normal activities of living eg work, education, family & community life.

I am appealing to you to support the rights of citizens in this state to have the reinstatement of mandatory reporting of + test results. Thus raising public awareness of the risk for contracting LYME DISEASE. The establishment of a State Task Force on LYME DISEASE to study & recommend a state-wide plan for controlling this infectious disease.

Thank You for taking time to hear & consider this testimony.

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